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The Role of Interactive and Critical Health Literacy in Appointment Cancellations: A Quality Assurance Survey

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THE ROLE OF INTERACTIVE AND CRITICAL HEALTH LITERACY IN APPOINTMENT CANCELLATIONS: A QUALITY ASSURANCE SURVEY

by

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ABSTRACT

THE ROLE OF INTERACTIVE AND CRITICAL HEALTH LITERACY IN APPOINTMENT CANCELLATIONS: A QUALITY ASSURANCE SURVEY

by

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Objective: An agency located in the Midwest identified a 30 percent cancellation rate in their federally funded Part C early intervention (EI) program. Parents and caregivers of children with developmental delays tend to access and utilize the health care system and programs aimed at improving developmental outcomes more frequently. These children will likely benefit from caregivers who have ample health literacy to navigate the complicated systems of care. Although the role of functional health literacy (i.e., reading and numeracy skills) on health and developmental outcomes is well documented in the literature, limited research exists on the importance of interactive and critical health literacy on successful navigation and informed-decision making. Thus, this research sought to establish the role of caregivers' interactive and critical health literacy on level of attendance in the EI program.

Background: The most common measures of health literacy, the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA), appear to be both valid and reliable assessment tools (Davis et al., 1993; Parker et al., 1995). However, these measures are not always true indicators of an individual's level of health literacy (Freidman et al.,

2009); likely due to the exclusive focus on reading and numeracy skills (i.e., functional health literacy). Interactive and critical health literacy involves complex skills that individuals use to abstract, apply, evaluate, and analyze health-related information (Nutbeam, 2000). The purpose of this research is to provide support to the notion that interactive and critical health literacy is a vital construct and one that needs to be measured to better understand participation in developmental or EI programs.

Methods: Forty parents and caregivers with children enrolled in the EI program were recruited by their case coordinator at the center. Eligible participants were categorized as either 'low attenders' (≤ 50% of appointments) or 'regular attenders' (≥ 80% of appointments), and completed a 28-item questionnaire over the phone. Responses were transcribed and coded to develop an overall interactive and critical health literacy score which was used to assess the relationship with level of attendance.

Results: The findings from the binary logistic regression identified that participant interactive and critical health literacy score was a significant predictor variable to level of attendance, with an odds ratio Exp(B) = 1.962 (CI 95%, 1.016-3.791). These results indicate that participants with a higher health literacy score were almost 2 times more likely to be regular attenders than low attenders. It was also discovered that interactive and critical health literacy score had a statistically significant correlation with percent attendance in participants in the low attender group, $r = .598$, $n = 40$, $\rho < 0.0005$. Specifically, higher interactive and critical health literacy scores were associated with higher percent attendance.

Conclusion: This study lent support to the value of interactive and critical health literacy on cancellations rates. Results found interactive and critical health literacy scores to be both predictive and strongly correlated with appointment attendance. These findings suggest that the development of an instrument to measure the construct of interactive and critical health literacy may be possible. Developing instrumentation that spans beyond functional health literacy could lead to an improvement in the understanding of the role of interactive and critical health literacy in family participation in EI programs.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

I. INTRODUCTION

Early Intervention

The first few years of life are vital to a child's development. Reaching each developmental milestone is critical in order to prepare for his or her success in school-age and adult occupations (Park et al., 2014). For children with developmental delays (DD), early intervention (EI) services and parent education are imperative to improving their development. The Individuals with Disabilities Education Act (IDEA) 2004 stipulates that infants and toddlers ages 0-3 years who are eligible, should be provided early intervention (Part C) services and an individualized family service plan (IFSP) as soon as their delays have been detected to prevent further problems and help them succeed (Opp, 2009). Fortunately, EI services have consistently been documented in the literature to produce positive developmental and behavioral outcomes for children ages birth to three with developmental delays (DD: Jimenez et al., 2013; Opp, 2009; Park et al., 2014).

An agency located in a city in the Midwest provides EI services to children with DD due to congenital or acquired mental or physical deficits. Currently, 30 percent of scheduled appointments in their EI program are cancelled. While common reasons given for cancellations in primary health care include: forgetting about the appointment, mix up over the date/time of the appointment, traffic, and oversleeping (George & Rubin, 2003), the level of health literacy may be an important contributing factor that is often overlooked.

The World Health Organization (WHO) defines health literacy as cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health (WHO, 2014). Health literacy is commonly thought of as an individual's ability to read health information, but it is much more than that. Rather, it is a shared responsibility in which patients *and* health care providers each must communicate in ways the other can understand (Osborne, 2005). The complexity of skills, both cognitive and communicative, that are necessary for an individual to successfully navigate the health care system requires a more thorough look at how we define health literacy.

Health Literacy: Beyond Reading and Writing

In 2000, Donald Nutbeam proposed a model for health literacy that continues to be widely cited in current literature as useful for analyzing literacy skills required in a number of health situations (Mitchell & Begoray, 2010). Nutbeam had criticized prior definitions of health literacy as being too narrow and lacking the deeper purpose of literacy to an individual (Gray et al., 2005). According to Nutbeam, health literacy can be divided into three levels: functional literacy, interactive literacy, and critical literacy. The model established by Nutbeam is adopted in this research.

At the most basic level, functional literacy refers to the ability to apply basic literacy skills to health-related materials, such as reading the label on a pill bottle (Nutbeam, 2000). Basic reading and writing skills, as well as numeracy skills, are critical to navigating health-related information at this level. Next is interactive

literacy which is predicated upon functional health literacy and requires more advanced cognitive skills along with social skills. At this level, patients can retrieve and apply information derived from various forms of communication (Nutbeam, 2000). Critical literacy, the highest level, builds on functional and interactive literacy. In critical literacy, patients are able to evaluate health issues, determine challenges and advantages of each, and recognize the risks and benefits as well as advocate for themselves and others (Mitchell & Begoray, 2010). Together, interactive and critical health literacy involves complex skills that individuals use to abstract, apply, evaluate, and analyze health-related information (Nutbeam, 2000).

Purpose

Parents and caregivers of children with DD tend to access and utilize the health care system and developmental programs more frequently (Pizur-Barnekow et al., 2011), and these children will likely benefit from caregivers who have ample health literacy to navigate the complicated health care systems. Research has shown that parents and caregivers with low health literacy commonly report that they: 1) had difficulty contacting EI programs, 2) were confused about EI services, 3) had pediatricians who did not explain EI services and 4) were given written materials that were not helpful (Jimenez et al., 2013). It becomes vital then, for caregivers with low health literacy to be identified early so that supports can be provided to enhance access to and knowledge about EI service delivery. While functional health literacy skills (i.e. reading ability and numeracy skills) required to successfully navigate the healthcare system are well

understood, the importance of interactive and critical health literacy on successful navigation and informed decision-making still remains limited. Thus, this research sought to better understand the importance of interactive and critical health literacy skills on level of attendance in the EI program at an agency in the Midwest.

II. LITERATURE REVIEW

Current Measures of Health Literacy

The most commonly used methods to assess health literacy are the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA). The REALM is a screening tool for adult patients to assess their ability to read common medical words and lay terms for body parts and illnesses (NC Program on Health Literacy, 2014). It is a word recognition test and does not assess comprehension. The TOFHLA, on the other hand, consists of a reading comprehension section and numeracy section. Both sections are derived from common medical scenarios and have the subject answer questions regarding the information they read. The scoring on the TOFHLA categorizes respondents into inadequate, marginal, or adequate levels of health literacy (NC Program on Health Literacy, 2014).

Although the REALM and TOFHLA have been demonstrated to be both valid and reliable assessment tools (Davis et al., 1993; Parker et al., 1995), they focus solely on reading and numeracy skills (i.e. functional health literacy), completely omitting interactive and critical health literacy. This brings to question whether the REALM and TOFHLA are truly indicative of an individual's overall health literacy skills.

In 2009, Freidman and colleagues explored 25 African American men's understanding of prostate cancer by assessing their level of health literacy. Participants' health literacy was measured using the short form of the TOFHLA (S-TOFHLA). Focus groups were also conducted in which participants were

asked questions covering a variety of topics related to prostate cancer including prostate cancer risk, prevention, and screening. Results indicated that the average score on the S-TOFHLA identified participants as having “adequate” health literacy levels. Interestingly, when the participants were interviewed during the focus groups, they had limited understanding about prostate cancer risk factors and preventative behaviors; suggesting the scores on the S-TOFHLA were not true indicators of the participants’ health literacy. The S-TOFHLA only looks at an individual’s reading skills (NC Program on Health Literacy, 2014). While these are important skills to possess, the instrument fails to address the higher level cognitive skills required for interactive and critical health literacy proposed in Nutbeam’s model.

Support for Nutbeam’s model (2000) has been demonstrated in recent literature, specifically confirming the higher order cognitive processes necessary for interactive and critical health literacy. Pizur-Barnekow, Darragh, and Johnston (2011) conducted focus groups with thirty-five caregivers of children with special health care needs to identify the skills caregivers deemed necessary to successfully manage their child’s care. During the focus groups, participants described six cognitive processes (e.g. remember, understand, apply, analyze, evaluate, and create) in addition to three communicative processes (e.g. facilitate and mediate between health care professionals, assertion through maintaining or defending their child’s rights, and aggress or boldly pursue health-related care in a forceful manner) that were necessary to promote optimal health for their child (Pizur-Barnekow et al, 2011). Of importance, were the six cognitive processes

discussed by caregivers; all of which fell closely in line with Nutbeam's model for interactive and critical health literacy. Moreover, the six cognitive processes described by caregivers were analogous to Bloom's Revised Taxonomy, a continuum of cognitive skills from simple to complex (Pickard, 2007) needed to make informed decisions. These findings suggest the potential for a taxonomic code of cognitive skills needed for interactive and critical health literacy. If a taxonomy of interactive and critical health literacy skills exists, an instrument developed to measure the construct of interactive and critical health literacy may be possible; leading to an improvement in the adequacy of screening tools aimed at identifying those at risk for low interactive and critical health literacy.

Populations at Risk for Low Health Literacy

The prevalence of low health literacy in developing countries, like the United States, is surprisingly high. Addressing solutions to this problem is one of the national objectives in Healthy People 2020 (U. S. Department of Health and Human Services, 2012). According to the National Assessment of Adult Literacy (NAAL), approximately 36 percent of adults in the United States have limited health literacy; 22 percent of those adults have basic and 14 percent have below basic. Additionally, another 5 percent of the U.S. population is not literate in English and only 12 percent have what is considered to be proficient health literacy (National Networks of Library of Medicine, 2014).

The literature has found similar results when assessing adults' health literacy in the United States. One systematic review analyzed 85 studies that measured health literacy and found over half the adults included had limited health literacy.

In particular, 26 percent had low health literacy and an additional 20 percent had marginal health literacy (Paasche-Orlow et al., 2005). Another relevant finding was low health literacy was significantly associated with ethnicity, level of education, and age (Paasche-Orlow et al., 2005). Specifically, individuals who were African American, had not completed high school, or were 50 years and older all had a higher prevalence of low health literacy (Paasche-Orlow et al., 2005).

Unfortunately, an analysis of the percentage of adults in the U.S. with basic and below basic health literacy depicts significant disparities among ethnic and minority groups. In particular, there are consistent findings that Caucasian adults have a higher average health literacy level compared to African Americans, Hispanics, and American Indian/Alaska Natives (Paasche-Orlow et al., 2005). In fact, in 2003 only 2 percent of the African American population had proficient health literacy compared to 24 percent of Caucasians, and nearly a quarter of the African American adult population was below a basic level of proficiency (Kutner, Greenberg, Jin, & Paulsen, 2006). Weekes (2012) conducted a systematic review on health literacy in the African American population and found that health literacy influences African American's understanding of informed consent, understanding of diseases, perceived susceptibility, adherence to medical protocols and medication administration. Perhaps more noteworthy, is the issue that there tends to be an overestimation by health care providers regarding the level of health literacy in ethnic minority populations.

In a study examining whether healthcare providers accurately perceived individuals with HIV as being at risk for low health literacy, the authors found that healthcare providers identified 53 percent of clients as having adequate health literacy when in fact these clients were low health literate (Ohl et al., 2010). Furthermore, Kelley and Haidet (2007) conducted a study on 12 non-academic primary care physicians and 100 patients to compare patient literacy level with physicians' ratings of their patient's literacy level. Patients' health literacy was measured using the REALM, and results demonstrated a significant discrepancy between patient REALM level and physician rating. While patient's REALM level was not statistically significantly associated with ethnicity, physicians overestimated the literacy level of 54 percent of African American clients in comparison to only 11 percent of white non-Hispanic patients (Kelley & Haidet, 2007).

These findings imply that health care providers are often unaware when their patients have low health literacy skills. Moreover, health care providers tend to overestimate patient literacy level at an overwhelmingly high rate in ethnic minorities. This can lead to major implications on health and developmental outcomes, especially among ethnic minorities; a large proportion of families served at the EI program involved in this research. As a result, health literacy intervention strategies must target at-risk populations. In order to accomplish this, EI providers need to be able to accurately identify those parents and caregivers at risk, as well as recognize that while health literacy was once viewed as a deficit on the part of the persons seeking services, we now know that health

literacy is a “systems issue” (Rudd, 2010). Consequently, improving health literacy will continue to be dependent upon the presentation of health and developmental information by the service provider; both written and verbal.

Interventions for Improving Health Literacy

Lower functional health literacy is associated with poorer health outcomes including more hospitalizations, greater use of emergency care, poorer ability to interpret health messages, and poor use of preventative services (Berkman et al., 2011; Kutner, 2006). Ultimately, poor functional health literacy can be attributed partly to the high level of literacy skills needed to fully comprehend a large proportion of written and oral health information communicated between physicians and patients and their family members (Williams et al., 2002). A study conducted by Pizur-Barnekow et al. (2010) evaluated the readability and accessibility of EI program literature of nine agencies in the Midwest. Results demonstrated that the documentation families received from EI programs were written at an average grade level of 9.5; significantly higher than the recommended fifth-grade level (Pizur-Barnekow et al., 2010).

Similar results were found when looking at the readability of individualized family service plans (IFSP). In a study analyzing 85 IFSPs from seven agencies in the Midwest, none of the agencies had prepared the documents at or below the recommended fifth grade reading level. In fact, the average reading level of the IFSP documents were 8.0, indicating that the text was written at the 8th grade level (Pizur-Barnekow et al., 2010). Research has demonstrated that written documentation is often at a level well above the recommended fifth grade

reading level, negatively impacting the parents' ability to participate in their child's EI services. Other studies are suggesting that service providers' verbal communication can have negative effects on health literacy as well (Bennett et al., 2006).

Service Provider Influence. Bennett et al. (2006) conducted focus groups with 202 African American women of low (<6th grade) and high literacy levels to assess patient-clinician communication and the effect on adherence to prenatal care. Results showed that the quality of communication between the patient and the provider was described as either a motivator or an obstacle to prenatal care for women in every focus group (Bennett et al., 2006). Participants stated four clinician characteristics that influenced effective communication: clarity, continuity of care, trust, and close patient-physician relationship (Bennett et al., 2006). Poor client-provider communication, across *all* literacy levels (i.e. inadequate, marginal, and adequate), was associated with non-compliance in keeping appointments in prenatal care. These results suggest that improving written and verbal communication through health literacy interventions may lead to an increase in patient understanding as well as patient participation and adherence to appointments. Two strategies that may help improve service providers' written and verbal communication are pictorial image and teach back strategies.

Pictorial Image and Teach Back. Both pictorial image and teach back strategies have shown to be effective at increasing understanding of health information (Negarandeh et al., 2012; Villaire & Mayer, 2007; Wilson et al., 2011). Pictorial image involves adding pictures to written and verbal information.

Pictorial aids help to improve recall, comprehension and adherence (Negarandeh et al., 2012) in addition to being an easy tool to incorporate into appointments. Teach back, conversely, involves asking patients to repeat back in their own words what they need to know or do (Schillinger et al., 2003). The patient is asked to restate what they have learned back to the health care provider. This should not be a test of the patient, but rather how well the health care provider explained a concept (Schillinger et al., 2003). The health care provider then tailors each teaching and reassesses the patient's comprehension until the patient has mastered the information (Negarandeh et al., 2012). Ultimately, the goal is for teach back to help close the loop between patient education and patient understanding.

It is important to note that patients with low health literacy may have negative feelings related to their limited reading ability or understanding. Similarly, the health care environment can make it hard for patients to tell providers they do not read well or do not understand (National Networks of Library of Medicine, 2014); further complicating health care providers' ability to successfully identify patients at risk for low health literacy. Utilizing health literacy intervention strategies like teach back, however, creates an opportunity to promote improved health literacy skills, regardless of the patients' current level of understanding.

Summary

An agency located in the Midwest has identified a 30 percent cancellation rate in their EI program. This high cancellation rate has become a chief concern for the service providers at this facility due to the cost and inefficiency associated with cancellations. The majority of families served at the EI program are primarily from ethnic minority backgrounds; a population identified in the literature as being at risk for low health literacy. Unfortunately, the current measures used in the field to screen for adults at risk for low health literacy are restricted to measuring only reading and numeracy skills and may not be true indicators of an individual's level of health literacy (Freidman et al., 2009). Consequently, a greater understanding of interactive and critical health literacy is needed in order to develop and promote more valid and reliable health literacy measurements. We know that lower [functional] health literacy is associated with poorer health outcomes, such as low appointment adherence, but the EI system is not responsible for improving a parent or caregiver's functional health literacy. EI programs however, can create health literate environments and services that enhance a caregiver's understanding of the program, and potentially increase participation. Successfully identifying parents and caregivers with low interactive and critical health literacy is crucial to improving family engagement which may in turn improve developmental outcomes for their child.

Thus, this research seeks to expand upon Nutbeam's model (2000) of health literacy and provide support for the taxonomy of cognitive processes (Pizur-Barnekow et al., 2011) by identifying the interactive and critical health

literacy skills of parents and caregivers of children enrolled in the EI program. More specifically, this research aims to better understand the role of parent and caregiver's interactive and critical health literacy on health outcomes; namely appointment cancellations.

III. METHODS

Research Design

A survey research design with quantitative data analysis methods was used to explore the understanding and experience of parents and caregivers with children enrolled in the EI program located in an urban area of the Midwest. A phone interview was selected as the most effective method to obtain data in order to address the source(s) of cancellations.

Variables

Dependent variable. The dichotomous dependent variable in this research was level of attendance. Parents and caregivers were either low attenders, meaning their child attended 50 percent or less of scheduled therapy appointments, or regular attenders if their child attended 80 percent or more of scheduled therapy appointments. The research team defined these two levels in order to ensure a sufficient gap existed between the two groups' attendance to detect any possible source of cancellation.

Independent variables. The independent variables were the items on the questionnaire, which represented the participant's *interactive and critical health literacy*, adopted from Nutbeam's model (2000). Interactive and critical health literacy was operationally defined by the research team as: the advanced cognitive skills, which together with social skills, can be used to extract information and derive meaning from different forms of communication, actively participate in everyday life, as well as critically analyze information to promote and maintain good health. The taxonomy of cognitive processes identified by

caregivers of children with special health care needs was also adopted in this research (Pizur-Barnekow et al., 2011). The six cognitive processes addressed in this study were: remember, understand, apply, analyze, evaluate, and create. ‘Remember’ refers to a caregiver’s ability to retain health-related information. In this cognitive process caregiver’s are able to list, recall, or reproduce relevant health information for their child’s care. ‘Understand’ refers to a caregiver’s ability to learn or know about health-related information. Caregivers are able to discuss, explain, locate or predict in this cognitive process. ‘Apply’ is the ability to put knowledge about health information to practical use. In this cognitive process a parent can choose, demonstrate, interpret, schedule, or solve health-related information. ‘Analyze’ refers to the ability to examine or separate into parts to determine function and interrelationships. Parents and caregivers can compare and contrast, prioritize, question, appraise, or criticize health information in this cognitive process. ‘Evaluate’ is the ability to determine the quality or value of information to make decisions related to their child’s health. In this cognitive process, parents are able to decide, appraise, argue or defend. The last cognitive process, ‘create,’ is the ability to make or design something that increases the caregiver’s ability to navigate the system. Parents are able to assemble, construct, create, develop, design, or plan health-related information.

Hypotheses

Hypothesis 1. It is first hypothesized that a significant difference in total interactive and critical health literacy scores will exist between the low attender and regular attender groups.

***Null Hypothesis 1*.** There will be no significant difference in total interactive and critical health literacy scores among low attenders and regular attenders.

***Alternative Hypothesis 1*.** The parents and caregivers in the 'low attender' group will have a lower interactive and critical health literacy score compared to the caregivers in the 'regular attender' group.

Hypothesis 2. The second hypothesis addressed the relationship between percent attendance and interactive and critical health literacy score.

***Null Hypothesis 2*.** There is no association between caregiver's percent attendance and their interactive and critical health literacy score, H_0: r = 0.

***Alternative Hypothesis 2*.** Parents and caregivers with a lower percent attendance will be associated with a lower interactive and critical health literacy score. Likewise, parents and caregivers with a higher percent attendance will be associated with a higher interactive and critical health literacy score, H_0: r > 0.

Participants and Recruitment

Prior to recruitment, the staff at the EI program compiled a list of potential participants that fell into either the low attenders (≤ 50% of scheduled therapy visits) or regular attenders (≥ 80% of scheduled visits), based on their attendance for scheduled therapy appointments (see Appendix A). Participants included in the study had to have the following criteria: (a) English speaking and/or Spanish speaking, (b) between the ages of 18-50 years, (c) a primary caregiver of a child enrolled in EI services, and (d) have a child enrolled in the services for a minimum of 3-6 consecutive months. Eligible participants were then recruited

through direct person-to-person contact by the service coordinators at the EI program.

The University of Wisconsin-Milwaukee Institutional Review Board (IRB) approved this research project (see Appendix B). IRB approval was also given to alter written informed consent. Participants were told the purpose of the interview (see Appendix C) and that their answers would be written down. Verbal consent was given and each participant was awarded a $5.00 gift card as an incentive to participate. Participants were awarded a gift card even if they did not answer all questions on the survey.

Instrumentation

The questionnaire used was developed after two phases. In the first phase, Preparation Phase, members of the research team and staff from the EI program met to define the issue the EI program wanted to address. After several meetings, the research team and staff from the EI program identified that the high (30 percent) cancellation rate would be addressed. Next, during the Inquiry Phase, the research team and staff from the EI program decided a telephone survey would be the optimal method to help determine the root causes for cancellations. A list of questions was developed and first pilot tested at a Family Support group meeting held at the EI center. Parents were read each question and asked to identify whether they were clear or unclear, and if rewording was necessary. Based upon parent feedback, the questions were revised and the questionnaire was developed. A second pilot test was done to assure validity of the questionnaire. A total of 10 parents and caregivers completed the phone

interview and responses indicated understanding of the questions. The final questionnaire had a total of 28-items (see Appendix D).

Procedures

Phone interviews were conducted by one data collector in a private conference room at the EI program center. No recording device was used during the interviews because the research team and staff at the EI program believed that recording interviews would lead to a high rate of attrition. Speaker phone was used to allow the researcher to record participant responses by hand. Demographic information was gathered prior to the start of each questionnaire. Participants provided their age, zip code, primary language, and the highest level of education completed. During data collection, the researcher was blind to the participant's group (low attender vs. regular attender) to prevent experimenter bias. Each interview lasted approximately 15 to 20 minutes.

A translator from the EI program was present for phone interviews with Spanish speaking participants. The translator explained the purpose of the study, obtained informed consent, gathered demographic information, and obtained responses for the 28-item questionnaire from each Spanish speaking participant. After every question, the translator stated the participant's response in English to allow the researcher time to transcribe the answers. The same translator completed the questionnaire for all of the Spanish speaking participants to promote reliability.

Data Analysis

A quantitative approach was used to analyze the participants' responses on the questionnaires. Two members of the research team read and coded the responses of the 28-item questionnaire to develop a 0-2 rating scale for each item; 2 indicating a higher interactive and critical health literacy score and 0 being lowest (Appendix E). Each item on the questionnaire was labeled according to the cognitive process necessary for interactive and critical health literacy the item covered. Similar items on the questionnaire were then grouped together to develop six cognitive processing sub scores (See Table 1). Item 6 was excluded from the cognitive sub scores and became its own independent variable because it addressed the location of therapy appointments. Additionally, items 8, 22, 23, and 24 were excluded from the six cognitive sub scores because they did not address interactive and critical health literacy. All four items addressed the participants' perceived level of comfort and respect from the EI program staff. These four items were combined as a separate independent variable, *perception of staff*, and later analyzed along with age, education, and primary language.

Table 1

Six Cognitive Sub Scores

Apply Total	Understand Total	Remember Total	Analyze Total	Evaluate Total	Create Total
Q1	Q2	Q7	Q9	Q10	Q14
Q17	Q3	Q12		Q11	Q28
Q18	Q4	Q13		Q20	
Q27	Q5	Q15		Q25	
	Q21	Q16		Q26	
		Q19			

(See Appendix G for Table 1 Text Description)

Each participant's six sub scores were then summed to get a total interactive and critical health literacy score. Participants' demographic information and scores for the questionnaire were entered into a spread sheet for data analysis using SPSS software.

Binary logistic regression predicts the probability of an event occurring and is used if the dependent variable is dichotomous in nature (Portney & Watkins, 2009). It determines if the independent variables can predict whether an individual is likely to belong to one of the two levels of the dependent variable. In this study, the research team sought to assess whether the six cognitive process sub scores and the total (interactive and critical) health literacy score would predict participants' level of attendance (dependent variable). It was hypothesized that participants in the low attender group would have lower interactive and critical health literacy scores. Likewise, participants categorized as regular attenders would have higher interactive and critical health literacy scores. Thus, to address the first hypothesis, a binary logistic regression using a hierarchical block entry method was used to assess the probability that the independent variables would predict the likelihood participants belonged to the regular attender group. Independent variables included: demographic information (age, education), the six cognitive sub scores, and the total interactive and critical health literacy score.

The second hypothesis addressed the relationship between percent attendance and total interactive and critical health literacy score. Pearson *r* indicates the extent to which a linear relationship exists between two

quantitatively measured variables (Meyers, Gamst, & Guarino, 2006). In this study, percent attendance and interactive and critical health literacy scores were both continuous and quantitatively measured variables, thus Pearson's correlations were run. Demographic information (i.e. age and education level) was also included in a Pearson's correlation.

IV. RESULTS

Participant Demographics

A total of 40 parents and caregivers participated in the study (regular attenders, n = 34; low attenders, n = 6). Twenty-five caregivers were Spanish speaking adults and 15 were English speaking. The age of participants ranged from 21 years to 43 years, with an average education at the 10.8 grade level. Complete demographic information for participants is detailed in Table 2.

Table 2

Participant Demographics

Characteristic	Numeric or narrative description
Level of Attendance (*n*=40)	
low attender 6	Mean = 41.0% attendance
regular attender 34	Mean = 89.2% attendance
Primary Language (*n*=40)	
English 15	
Spanish 25	
Age	Mean = 31.9yrs; Range = 21yrs to 43 yrs
Level of Education Completed	Mean = 10.8 grade level; Range = 5th to18th grade (Master's degree)

(See Appendix G for Table 2 Text Description)

Hypotheses

Hypothesis 1. Binary logistic regression was performed to assess the impact of a number of variables on the likelihood that participants would fall into the regular attender group. The model contained nine independent variables (age, education level, apply score, understand score, remember score, evaluate score, analyze score, create score, and total interactive and critical health literacy score). Null hypothesis 1 stated there would be no significant difference in

interactive and critical health literacy scores among low attenders and regular attenders. The alternative hypothesis 1 stated that parents and caregivers in the 'low attender' group would have a lower interactive and critical health literacy score compared to the caregivers in the 'regular attender' group. Results from the binary logistic regression are shown in Table 3 and illustrate that the alternative hypothesis 1 was supported.

Table 3

Binary Logistic Regression Predicting Likelihood of Regular Attender

IVs	*B*	S.E.	Wald	*df*	ρ	Odds Ratio	95.0% C.I. for Odds Ratio	
							Lower	Upper
Age	0.394	0.185	4.537	1	0.033	1.483	1.032	2.130
Education	0.270	0.324	0.696	1	0.404	1.31	0.694	2.473
Interactive & Critical Health Literacy Score	0.674	0.336	4.027	1	0.045	1.962	1.016	3.791
Constant	-35.438	17.75	4.027	1	0.046	0.000		

(See Appendix G for Table 3 Text Description)

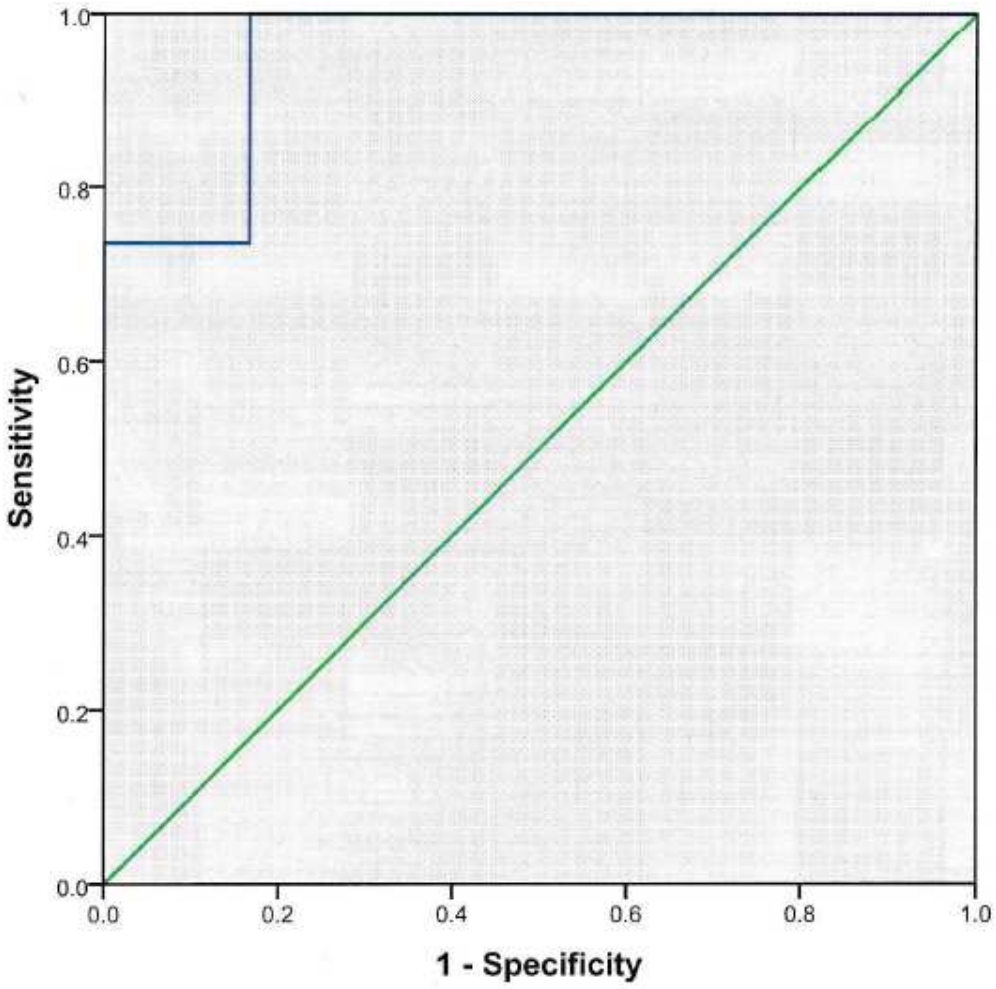
Although none of the six cognitive process sub scores made a significant prediction to level of attendance, two independent variables made a significant contribution to the model: total interactive and critical health literacy score and age. The interactive and critical health literacy score had an odds ratio Exp(B) = 1.962 (CI 95%, 1.016-3.791), signifying that participants with a higher interactive and critical health literacy score were nearly 2 times more likely to be regular attenders than low attenders. Likewise, the variable of 'age' had an odds ratio

Exp(B) = 1.483 (CI 95%, 1.032-2.130), indicating older participants were 1.48 times more likely to be in the regular attender group.

The full model containing all predictors was also statistically significant, X^2 (3, N = 40) = 19.364, ρ < .001, indicating that the model was able to distinguish between participants who were in the low attender and regular attender group. The model as a whole correctly classified 95 percent of cases. This indicates the questionnaire was able to correctly predict the participants' attendance level (regular attender/low attender) for 95 percent of the sample. An ROC curve was created to assess the model's sensitivity and specificity to identify participant's level of attendance. An area of 1.0 under the curve indicates a perfect test; one that is both sensitive and specific. Sensitivity refers to a test's ability to obtain a positive test when the target condition is really present (Portney & Watkins, 2009). In this study, 'regular attender' was considered the target group. Therefore, sensitivity measured how well the scores on the questionnaire correctly identified a participant as a regular attender if they were in fact in the 'regular attender' group. Specificity on the other hand, refers to the test's ability to obtain a negative test when the condition is really absent (Portney & Watkins, 2009). In this study, specificity assessed how well the scores on the questionnaire correctly identified a participant as a low attender when they were in fact in the 'low attender' group. Results of the ROC curve indicate that the model was both sensitive and specific for predicting level of attendance. Figure 1 depicts the ROC curve with an area of 0.956, indicating that the questionnaire was nearly perfect at predicting level of attendance.

Figure 1

ROC Curve for Predicted Probability of Level of Attendance



Area	Std. Error	Asymptotic Sig[b]	Asymptotic 95% Confidence Interval	
			Lower Bound	Upper Bound
0.956	0.044	0.000	.870	1.000

(See Appendix G for Figure 1 Text Description)

Hypothesis 2. Null hypothesis 2 stated there would be no association between percent attendance and interactive and critical health literacy scores. The alternative hypothesis 2 stated there would be a significant correlation between the two variables. The findings from the Pearson Correlation indicate the alternative hypothesis 2 was supported (See Table 4).

Table 4

Correlation Matrix for Percent Attendance and Health Literacy Score

		Interactive and Critical Health Literacy Score	Percent Attendance
Interactive and Critical Health Literacy Score	Pearson Correlation	1	.598**
	Sig. (2-tailed)		.000
	N	40	40
Percent Attend	Pearson Correlation	.598**	1
	Sig. (2-tailed)	.000	
	N	40	40

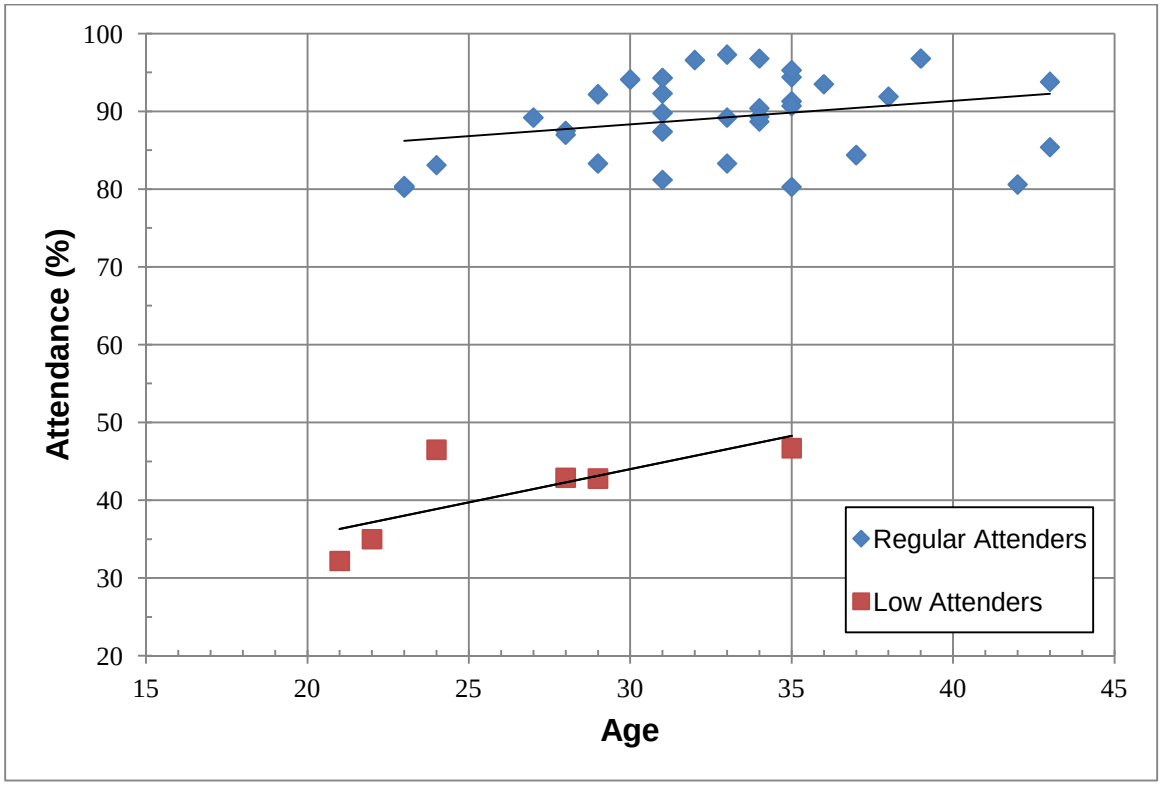
**Correlation is significant at the 0.01 level (2-tailed)

(See Appendix G for Table 4 Text Description)

While there were no significant correlations between any of the six cognitive sub scores and percent attendance, both age and total interactive and critical health literacy score had significant positive correlations. Age showed a moderate positive correlation with percent attendance in the low attender group, $r = .494$, $n = 40$, $\rho < 0.0005$. As depicted in Figure 2, as participants' age increased, their percent attendance increased. Recall that there were no participants included with percent attendance in the 51 percent to 79 percent range. This is shown by the separation in the graph between the low attender and regular attender group.

Figure 2

Correlation between Percent Attendance and Age

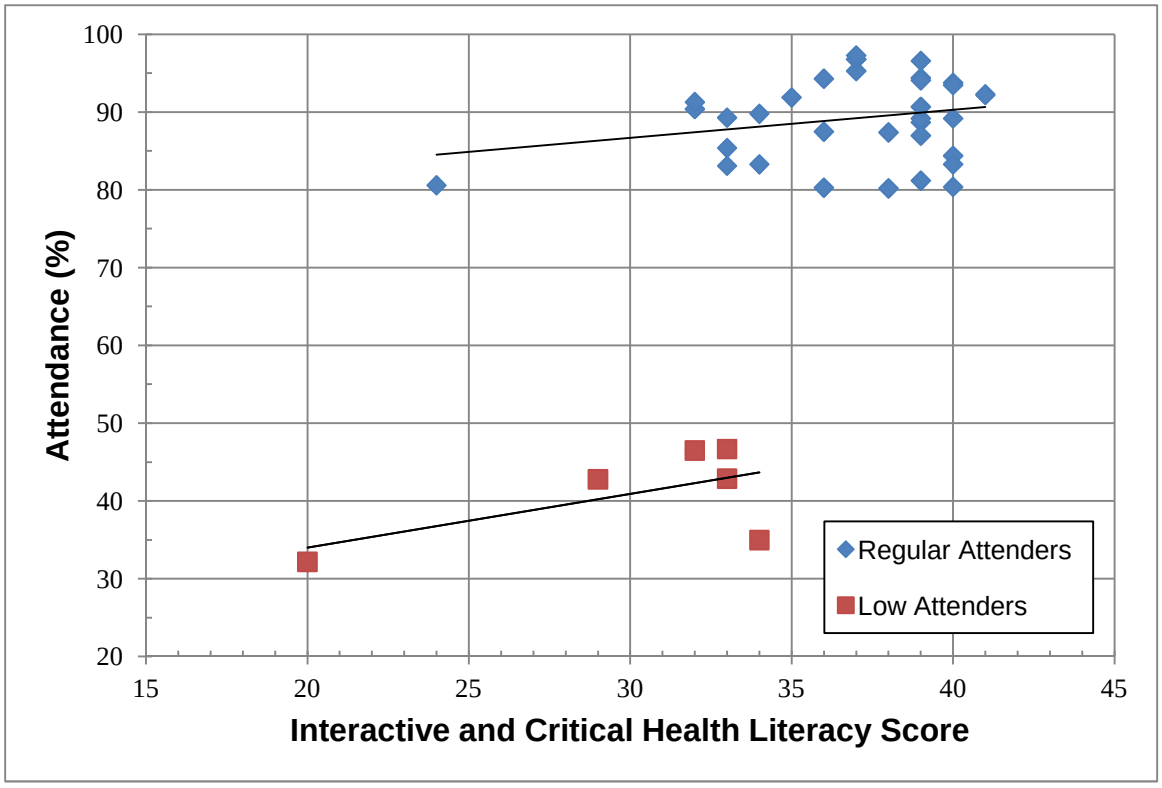


(See Appendix G for Figure 2 Text Description)

More noteworthy was the finding that total interactive and critical health literacy score showed a strong positive correlation with percent attendance in the low attender group, $r = .598$, $n = 40$, $\rho < 0.0005$. Figure 3 represents this correlation in a scatter plot, indicating that for low attenders, as percent attendance increased, participants' total interactive and critical health literacy score increased. Again, the gap between the low attender and regular attender group signifies the percent attendance range (51 percent to 79 percent) that was not included in this study. All of the participants' raw data and scores can be found in Appendix F.

Figure 3

Correlation between Percent Attendance and Health Literacy Scores



(See Appendix G for Figure 3 Text Description)

V. DISCUSSION

Implications of Findings

The results obtained from statistical analysis were consistent with both alternative hypotheses. This research sought to address the high 30 percent cancellation rate in the EI program located in a city in the Midwest. Specifically, this research aimed to determine: (1) the role interactive and critical health literacy played in level of attendance and (2) whether a relationship existed between percent attendance and participants' interactive and critical health literacy scores.

As previously stated, binary logistic regression indicated that both age and interactive and critical health literacy score were predictive variables of level of attendance. Older participants were nearly 1.5 times more likely to be in the regular attender group. This makes intuitive sense given older parents and caregivers are likely more mature, organized, and able to adhere to appointments through greater experience (and exposure) to the health care system. Of more interest was the finding that participants with higher interactive and critical health literacy scores were 1.962 times as likely to be in the regular attender group; implying that parents and caregivers with a higher interactive and critical health literacy score were nearly 2 times more likely to adhere to appointments. These findings are consistent with the literature on functional health literacy and health-related outcomes (Berkman et al., 2011; George & Rubin, 2003; and Kutner et al., 2006). Lower functional health literacy is associated with poorer ability to interpret health-related information and poorer

use of preventative services, like EI programs. The results from this study suggest that low interactive and critical health literacy is also associated with poorer use of preventative services; namely poorer participation and attendance in the EI program.

The binary logistic regression also found that none of the six cognitive sub-scores (apply, understand, remember, analyze, evaluate, and create) were significant predictive variables for level of attendance. This may be due to the small number of participants in the low attender group (n = 6), making it difficult to identify one or more variables that might play a larger role in assessing interactive and critical health literacy. Conversely, these results may lend support to Nutbeam's model (2000) of three typologies of health literacy; suggesting that all six cognitive processes are important for interactive and critical health literacy and all six should be assessed when screening for a patient's level of [interactive and critical] health literacy.

The second research question in this study looked at the relationship between percent attendance and interactive and critical health literacy. Demographic information was also assessed with percent attendance and age was the only factor that had a moderately significant correlation with percent attendance. Again, it seems intuitive that parents and caregivers who are older will tend to be more reliable in adhering to appointments based on their increased exposure and experience with the health care system. The most notable finding, however, was the strong positive correlation between percent attendance and interactive and critical health literacy score in the low attender group. The results of the

Pearson's correlation indicated that as caregivers' percent attendance in the low attender group increased, their interactive and critical health literacy scores also increased. Understanding the relationship between caregiver level of interactive and critical health literacy and percent attendance can assist the service providers at the EI program in targeting health literacy intervention strategies at their center.

Another notable statistical finding was the sensitivity and specificity of the model used in this research. Recall that the area under the ROC curve was 0.956 and an area of 1.0 indicates a perfect test. These findings suggest that the questionnaire used in this research was able to accurately determine whether a participant was a regular attender versus a low attender.

Limitations

Although the research team took steps to control as many conditions as possible, random measurement errors could have affected participants' scores on the questionnaire. Participants may have misunderstood the question being asked and as a result, influence their scoring on that item. There was no recording device used during the phone interviews and consequently, caregiver responses were not word-for-word. The use of a translator further limits the accuracy of participant responses in the Spanish speaking population, threatening reliability and validity of the results. However, scoring of the items was done through extraction of themes in participant responses; reducing the necessity for participant responses to be verbatim.

During data collection, the researcher was blind to the participants' level of attendance to lessen experimenter bias during the interview. As a result, the research team was unable to control for the sample size in each group. There were a total of 40 participants that completed the questionnaire and included in data analysis. This relatively small sample size, particularly in the low attender group (n = 6) and the fact that the data was collected from parents of children enrolled in one program, presents a threat to the external validity of the results. Furthermore, caution must be given when interpreting the correlations found in this study. The use of a dichotomous dependent variable left a gap in the data for percent attendance. There were no participants included in the data set with percent attendance ranging from 51 percent to 79 percent, thus potentially skewing the *r* value. Future research would need to include this range of percent attendance to determine if the positive correlation remains.

A number of extraneous variables may have influenced the findings in this study. Data collection took place during the morning hours and was completed by one researcher for all participants. It may be possible that all participants included in the study were not working or busy, and as a result, available to complete the phone interview. Additionally, there are obvious methodological difficulties in identifying reasons for non-attendance. Previous studies have demonstrated that patients who are considered 'non-attenders' are less likely to respond to questionnaires (George & Rubin, 2003), potentially leading to the disparity in sample size in this study between the low attender (n = 6) and regular attender (n = 34) groups. Lastly, this study took place within one agency located

in an urban city in the Midwest, greatly limiting the generalizability. Additional studies will be needed, especially with a larger ‘low attender’ group, in order to generalize these findings to a wider population.

Significance of Findings for Further Research

The specificity and sensitivity of the questionnaire, in addition to the strong positive correlation found between participants’ percent attendance and their interactive and critical health literacy brings exciting implications. If this holds true, it would suggest that the questionnaire may be an appropriate tool for identifying individuals’ level of attendance. Furthermore, the strong relationship between level of attendance and level of interactive and critical health literacy found in this study suggests the potential for identifying those at risk for low interactive and critical health literacy.

The literature has shown that current measures only assess functional health literacy and are not always true indicators of an individual’s health literacy skills (Freidman et al., 2009). The findings from this research suggest that an instrument, that is both specific and sensitive, could be developed to measure the construct of interactive and critical health literacy; supplementing the instruments that already exists. In this study, participants in the low attender group all scored 34 or below, out of a possible 46 points on the interactive and critical health literacy questionnaire. Due to the small sample of low attenders (n = 6), it is difficult to state the true cutoff score for ‘low’ or ‘inadequate’ interactive and critical health literacy. Future studies need to include larger sample sizes to determine if a cutoff score exists, and if so, what that score would need to be in

order to successfully identify adults as having ‘inadequate’ versus ‘marginal’ versus ‘adequate’ interactive and critical health literacy.

Clinical Significance. Participation in EI programs and parent education are both imperative to successful developmental and behavioral outcomes for children with DD. Understanding that lower interactive and critical health literacy is associated with lower percent attendance highlights the importance of health literacy intervention strategies early on in developmental programs. Unfortunately, the literature demonstrates that service providers often have a tendency to overestimate adult’s health literacy and understanding of the health care system (Kelly & Haidet, 2007; Ohl et al., 2010). Service providers’ overestimation of adult’s health literacy level, along with the exclusive focus on functional health literacy in the current screening tools used to identify those at-risk, further highlights the need for an improvement in health literacy measures being used. By improving screening tools, EI service providers will be able to target health literacy intervention strategies at those who need it most. Likewise, it remains crucial for EI providers to utilize health literacy strategies, like teach back, regularly in their scope of practice.

Interventions such as teach back assess the caregiver’s higher order cognitive processing skills. Through teach back methods, parents and caregivers are given an opportunity to demonstrate their understanding of the EI program through recall, application, analysis, and evaluation of information. When parents and caregivers have a chance to communicate their understanding and knowledge of EI services, it provides an insight to the level of interactive and

critical health literacy skills the caregivers possess. This in turn, allows the EI service providers a chance to intervene immediately to promote health literate parents and caregivers, with the goal of improving parent education and participation in EI programs. Consequently, this may lead to positive developmental and behavioral outcomes for their child enrolled in EI services.

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Appendix A: Participant Percent Attendance

Participant	Scheduled Appt	# Missed	% Attend	Participant	Scheduled Appt	# Missed	% Attend
31	74	8	89.2	98	33	1	96.8
105	31	21	32.2**	20	49	5	89.8
4	75	8	89.3	8	569	111	80.5
5	69	6	91.3	110	89	3	96.6
89	31	6	80.6	115	77	44	42.9**
94	21	2	90.4	151	15	8	46.7**
97	30	5	83.3	91	24	4	83.3
148	20	13	35.0**	21	314	53	83.1
39	230	45	80.4	26	51	4	92.2
40	61	3	95.1	23	96	6	93.8
80	37	4	89.2	82	13	1	92.3
85	23	3	87	96	242	48	80.2
46	111	14	87.4	86	373	42	88.7
51	37	3	91.9	9	125	17	86.4
16	32	1	96.8	15	38	2	94.7
13	60	9	85	119	12	1	91.7
28	403	19	95.3	123	10	1	90
116	13	1	92.3	124	11	1	90.9
117	13	1	92.3	131	25	1	96
120	5	1	80	142	12	1	91.7
122	83	10	88	33	32	5	84.4
127	30	2	93.3	83	54	5	90.7
143	8	1	87.5	19	56	11	80.3
92	41	6	85.4	7	17	1	94.1
158	14	8	42.8**	41	89	12	86.5
101	36	2	94.4	84	37	1	97.3
90	35	2	94.3	132	31	2	93.5
139	11	2	81.2	12	63	3	95.2

**Participants that were in the 'low attender' group (≤50% of scheduled appointments)

Appendix B: IRB Approval

UNIVERSITY of WISCONSIN
UWMILWAUKEE
Department of University Safety & Assurances

Melissa Spadanuda
IRB Manager
Institutional Review Board
Engelmann 270
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New Study - Notice of IRB Exempt Status

Date: August 24, 2012

To: Kris Barnekow, PhD
Dept: College of Health Sciences

Cc: --------

IRB#: 13.058
Title: [redacted] Quality Assurance Phone Survey

After review of your research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol has been granted Exempt Status under Category 2 as governed by 45 CFR 46.101(b).

Unless specifically where the change is necessary to eliminate apparent immediate hazards to the subjects, any proposed changes to the protocol must be reviewed by the IRB before implementation. It is the principal investigator's responsibility to adhere to the policies and guidelines set forth by the UWM IRB and maintain proper documentation of its records and promptly report to the IRB any adverse events which require reporting.

It is the principal investigator's responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities the principal investigator may seek to employ (e.g., FERPA, Radiation Safety, UWM Data Security, UW System policy on Prizes, Awards and Gifts, state gambling laws, etc.) which are independent of IRB review/approval.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project

Respectfully,
[redacted]
Melissa C. Spadanuda
IRB Manager

Appendix C: Phone Interview Introduction

Good morning/afternoon/evening.

My name is ___. I am a therapy student at (UWM) and am calling on behalf of [redacted] about (child's name) participation in the Birth to 3 Program. Are you a parent or serve as a guardian for (child's name)? (If not, request to speak to a parent or guardian. If not available, request a day and time that would be convenient to call back. Confirm the best phone number to use.)

(When speaking to a parent or guardian:) I would appreciate your answers to questions about the Birth to 3 Program to help us improve the services provided by [redacted]. It would take about 20 minutes of your time to answer these questions on the phone. We are collecting this information to help improve services at [redacted] and as part of a quality assurance study. Your name or identifying information will not be connected with your responses so that we can keep your responses confidential. Your participation is voluntary and you can stop participating in this interview at any time. For your participation, you will receive a $5.00 giftcard from McDonalds. It is important that you understand that by answering the questions during this interview, you are giving permission to participate in this quality assurance study and for us to take notes about your answers.

Would you like to continue with the interview and is this a good time or can you suggest a day and time that would work better for you? (Confirm the best phone number if requested to call back.)

Before we begin with the questions about the services you receive at [redacted], I am going to ask you a few questions so that we can get to know you a little better.

Please tell me your age?

What is the zipcode where you live or a major street/intersection?

What language do you prefer to use when talking with others? Would you describe English as your primary language?

What is the highest level of education you have completed?

(After completing the questions:) Thank you very much for your time in answering these questions. It will be very helpful to us in improving the services in the Birth to 3 Program at [redacted]. If you have questions or

concerns about the Program at any time, please call [redacted] at (phone number).

Appendix D: 28-Item Questionnaire

Question

1) How did you get involved in Birth to 3 ([redacted])? Did you make the referral? Did your doctor make the referral? If not, who did make the referral?
   Comments:

2) Were you or are you concerned about your child's development?
   Comments:

3) How was the Birth to 3 Program explained to you? Is it what you thought it would be?
   Comments:

4) What do you expect your child to accomplish in Birth to 3 or through [redacted]?
   Comments:

5) Are you aware that the Birth to 3 Program or the services that [redacted] offers are voluntary?
   Comments:

6) Where does your child receive services from [redacted] (at [redacted] or at home)?
   Comments:

7) If your child comes to [redacted], do you have transportation?
   Comments:

8) If your child is seen at home, are you comfortable with the therapists coming into your home?
   Comments:

9) Are there challenges in having therapists from [redacted] come to your home?
   Comments:

10) What do you like best about the services your child receives through [redacted]?
    Comments:

11) What don't you like about the services your child receives through [redacted]?
    Comments:

12) What types of services does your child receive through [redacted]? For example does your child receive therapy, education? Who are the providers…can you tell me their names?
    a. ***We may want to compare with the chart to see if the parent's perception matches the IFSP.
    Comments:

13) Does your child receive multiple services or one service?
    Comments:

14) If you don't know the types of services your child receives, what would help you remember?
    Comments:

15) Who provides service coordination for your child?
    Comments:

16) What time is your child's therapy scheduled for? Is it in the morning or afternoon?
Comments:

17) Does this time work well for you and your family?
Comments:

18) Is it difficult to meet with the therapists due to work?
Comments:

19) Do your therapists call you before your appointment?
Comments:

20) Do the activities that the therapists suggest that you do with your child (when the therapist isn't there) fit into your daily routine?
Comments:

21) Do you understand the purpose of the activities that the therapists suggest?
Comments:

22) Do the therapists treat you and your family with respect?
Comments:

23) Do the therapists respect your family values?
Comments:

24) Do you feel comfortable talking to the staff about something that concerns you?
Comments:

25) What do you like the most about the therapists from [redacted]?
Comments:

26) What do you like the least about the therapists from [redacted]?
Comments:

27) How do you cancel appointments with the [redacted] therapists?
Comments:

28) Are there any other questions that we should ask families that would help us understand how to improve services?
Comments:

Appendix E: 28-Item Scoring

Interactive and Critical Health Literacy Scoring for Items on Questionnaire

- 0-2 scale
- Higher score (2) is positive

1. Self-referral (2pts)
   Health care professional (1pt)
   Don't know (0pts)

2. Yes, have a concern (2pts)
   A change in level of concern (1pt)
   No concerns (0pts)

3. Gave detailed explanation (2pts)
   Simply state "yes what I thought" (1pt)
   Don't recall/know (0pts)

4. Give detailed explanation (2pts)
   General response: "get better" or "to help/to improve" (1pt)
   Don't know (0pts)

5. Yes (2pts)
   No (1pt)
   Don't know (0pts)

6. Correct response (2pts)
   Incorrect response (1pt)
   Don't know (0pts)

7. Have transportation (2pts)
   Don't have transportation (1pt)

8. Yes (2pts)
   No (1pt)

9. No (2pts)
   Yes (1pt)

10. State positive (2pts)
    State nothing they like (1pt)
    Don't know (0pts)

11. No complaints/dislikes (2pts)
    Have complaints/dislikes (1pt)
    Don't know (0pts)

12. Correctly identifies both name and services (2pts)
    Correctly identifies either therapist or service (1pt)
    Can't recall (0pts)

13. Recall correctly (2pts)
    Incorrect response (1pt)
    Cannot recall (0pts)

14. Offer specific suggestion (2pts)
    Don't offer suggestion (1pt)

15. Give correct name (2pts)
    Give an incorrect name (1pt)
    Don't know (0pts)

16. Gives specific time (2pts)
    Gives general time: morning/afternoon (1pt)
    Doesn't know (0pts)

17. Yes (2pts)
    No (1pt)
    Don't know (0pts)

18. No (2pts)
    Yes (1pt)
    Don't know (0pts)

19. Yes (2pts)
    No (1pt)
    Don't know (0pts)

20. Yes (2pts)
    No (1pt)
    Don't know (0pts)

21. Give a specific purpose (2pts)
    Give general purpose: "to help"/"to get better"/'yes" (1pt)
    No (0pts)

22. Yes (2pts)
    No (1pt)
    Don't know (0pts)

23. Yes (2pts)
    No (1pt)

Don’t know (0pts)

24. Yes (2pts)
    No (1pt)
    Don’t know (0pts)

25. State positives (2pts)
    State nothing positive (1pt)
    Don’t know (0pts)

26. State no dislikes (2pts)
    State dislike (1pt)
    Don’t know (0pts)

27. Give specific way: identify who call/time frame (2pts)
    General way: “by phone”/”call” (1pt)
    Don’t know (0pts)

28. Give more than 2 suggestions (2pts)
    Give 1 or 2 suggestions (1pt)
    Give no suggestions (0pts)

Appendix F: Raw Data

Appendix F.1: Demographic Information

Key for Data Entry			
Level of Attendance	Primary Language	Comfort/Perception of Staff	Location of Appt
Low Attender = 0	English = 0	Comfortable/Positive = 0	Center = 0
Regular Attender = 1	Spanish = 1	Uncomfortable/Negative = 1	Home = 1
			Both = 2

Participant	Level_Attend	Age	Education	Perception	Primary_Lang	Appt_Location	Pct_Attend
33	1	37	14	0	0	2	84.4
86	1	34	6	0	1	0	88.7
96	1	23	6	0	1	0	80.2
82	1	31	16	0	1	2	92.3
23	1	43	18	0	0	1	93.8
26	1	29	16	0	0	0	92.2
21	1	24	14	0	0	0	83.1
91	1	33	12	0	1	2	83.3
151	0	35	10	0	0	1	46.7
115	0	28	8	0	1	0	42.9
110	1	32	5	0	1	2	96.6
20	1	31	7	0	1	0	89.8
101	1	35	8	0	1	0	94.4
158	0	29	12	0	0	1	42.8
92	1	43	12	0	1	2	85.4
105	0	21	7	0	1	1	32.2
53	0	24	10	0	1	0	46.5
98	1	34	5	0	1	2	96.8
31	1	33	16	0	0	0	89.2
143	1	28	14	0	0	1	87.5

Key for Data Entry			
Level of Attendance	Primary Language	Comfort/Perception of Staff	Location of Appt
Low Attender = 0	English = 0	Comfortable/Positive = 0	Center = 0
Regular Attender = 1	Spanish = 1	Uncomfortable/Negative = 1	Home = 1
			Both = 2

Participant	Level_Attend	Age	Education	Perception	Primary_Lang	Appt_Location	Pct_Attend
28	1	35	7	0	1	0	95.3
16	1	39	10	0	1	0	96.8
51	1	38	14	0	0	1	91.9
46	1	31	14	0	0	2	87.4
85	1	28	9	0	1	0	87
80	1	27	12	0	1	0	89.2
39	1	23	12	0	0	0	80.4
97	1	29	8	0	1	1	83.3
94	1	34	12	0	1	1	90.4
89	1	42	12	0	1	0	80.6
5	1	35	6	0	1	1	91.3
4	1	34	9	0	1	1	89.3
83	1	35	12	0	1	0	90.7
90	1	31	5	0	1	0	94.3
139	1	31	14	0	0	1	81.2
132	1	36	18	0	0	2	93.5
84	1	33	10	0	0	2	97.3
7	1	30	12	0	1	2	94.1
19	1	35	12	0	1	1	80.3
148	0	22	10	0	0	1	35

Appendix F.2: Participant 'Apply' and 'Understand' Scores

Participant	Q1	Q17	Q18	Q27	Apply_Tot	Q2	Q3	Q4	Q5	Q21	Understand
33	1	2	2	2	7	2	2	2	2	2	10
86	1	2	2	2	7	2	0	2	2	1	7
96	0	2	2	2	6	2	1	2	2	1	8
82	2	2	2	2	8	2	1	2	2	1	8
23	1	2	2	2	7	1	2	2	2	2	9
26	2	2	2	2	8	2	2	2	2	2	10
21	1	2	1	2	6	2	2	1	2	1	8
91	1	2	2	2	7	2	1	2	1	2	8
151	1	2	2	2	7	2	2	2	2	1	9
115	1	2	2	2	7	1	2	1	2	1	7
110	1	2	2	2	7	2	1	2	2	1	8
20	1	2	2	2	7	2	1	2	1	1	7
101	1	2	2	999	5	2	2	2	1	1	8
158	1	2	1	1	5	2	1	2	2	2	9
92	1	2	1	1	5	2	1	1	2	1	7
105	0	1	1	1	3	2	0	1	2	0	5
53	1	2	1	2	6	2	1	0	2	2	7
98	1	2	2	2	7	0	2	1	2	1	6
31	1	2	2	2	7	2	2	2	2	2	10
143	1	2	2	2	7	1	2	2	1	2	8
28	1	1	2	2	6	2	2	2	1	1	8
16	1	2	2	2	7	2	0	2	2	1	7
51	1	2	2	1	6	0	2	2	2	1	7
46	1	2	2	1	6	1	2	2	2	2	9
85	1	2	2	2	7	2	1	1	2	2	8
80	1	2	1	2	6	2	2	2	2	1	9
39	1	2	1	2	6	2	2	2	2	2	10
97	1	2	2	2	7	2	1	2	2	1	8
94	1	2	2	1	6	0	2	2	2	1	7
89	1	2	2	1	6	0	1	1	2	1	5
5	99	1	2	2	5	2	1	2	1	1	7
4	0	1	1	2	4	2	2	0	2	1	7
83	1	2	2	2	7	2	2	2	2	1	9
90	1	2	2	2	7	0	1	1	2	1	5
139	1	2	2	2	7	2	2	1	2	2	9
132	2	2	2	2	8	2	2	2	2	1	9
84	1	2	2	1	6	2	2	2	1	2	9
7	1	2	2	2	7	2	2	1	2	2	9
19	1	2	2	2	7	2	1	2	2	1	8
148	1	2	2	1	6	2	2	1	2	2	9

Score 99 = No response

Score 999 = Not applicable

Appendix F.3: Participant 'Remember' and 'Analyze' Scores

Participant	Q7	Q12	Q13	Q15	Q16	Q19	Remember_	Q9	Analyze_Tc
33	2	1	2	2	1	1	9	2	2
86	2	2	2	2	1	2	11	2	2
96	2	1	2	2	2	2	11	2	2
82	2	2	2	2	1	2	11	2	2
23	999	2	2	2	2	1	9	2	2
26	2	2	2	2	1	99	9	2	2
21	2	1	2	2	0	1	8	999	999
91	2	2	2	2	1	2	11	2	2
151	999	1	2	2	2	1	8	2	2
115	2	0	1	2	1	2	8	999	999
110	2	1	2	2	1	2	10	2	2
20	2	0	2	2	1	2	9	2	2
101	2	2	2	2	2	2	12	2	2
158	999	1	2	1	1	1	6	1	1
92	1	1	0	2	1	2	7	2	2
105	999	0	1	0	1	2	4	1	1
53	2	0	0	2	1	2	7	999	999
98	2	1	2	2	1	2	10	2	2
31	2	2	2	2	2	1	11	1	1
143	999	2	2	2	1	1	8	2	2
28	2	1	2	2	1	2	10	2	2
16	2	1	2	2	2	1	10	2	2
51	999	2	2	2	1	1	8	2	2
46	2	1	2	2	1	1	9	2	2
85	2	2	2	2	1	2	11	2	2
80	2	1	2	2	1	2	10	2	2
39	2	2	2	2	1	2	11	1	1
97	999	0	2	2	2	1	7	2	2
94	999	0	2	2	1	1	6	2	2
89	2	1	2	2	1	1	9	2	2
5	999	1	2	2	1	1	7	2	2
4	999	2	2	2	2	1	9	2	2
83	2	1	2	2	1	2	10	2	2
90	2	2	2	2	2	2	12	999	999
139	999	2	2	2	1	2	9	2	2
132	2	1	2	2	2	1	10	2	2
84	2	1	2	2	1	1	9	2	2
7	2	2	2	2	1	2	11	2	2
19	999	2	2	0	1	1	6	2	2
148	999	0	1	2	2	2	7	2	2

Score 99 = No response

Score 999 = Not applicable

Appendix F.4: Participant 'Evaluate' and 'Create' Scores

Participant	Q10	Q11	Q20	Q25	Q26	Evaluate_T	Q14	Q28	Create_Tot
33	2	2	2	2	1	9	1	2	3
86	2	2	2	2	2	10	2	0	2
96	2	2	2	2	2	10	1	0	1
82	2	2	2	2	2	10	2	0	2
23	2	2	2	2	2	10	2	1	3
26	2	2	2	2	2	10	2	0	2
21	2	1	2	2	2	9	2	0	2
91	2	2	2	2	2	10	2	0	2
151	1	1	0	2	1	5	2	0	2
115	2	2	2	2	2	10	1	0	1
110	2	2	2	2	2	10	2	0	2
20	2	99	1	2	2	7	2	0	2
101	2	2	2	2	2	10	2	0	2
158	0	1	2	2	1	6	2	0	2
92	2	2	2	2	2	10	2	0	2
105	1	1	2	1	1	6	1	0	1
53	2	2	2	2	2	10	2	0	2
98	2	2	2	2	2	10	2	0	2
31	2	1	2	2	1	8	2	1	3
143	2	1	2	2	2	9	2	0	2
28	2	2	2	2	2	10	1	0	1
16	2	2	2	2	2	10	1	0	1
51	2	2	2	2	2	10	1	1	2
46	2	2	2	2	2	10	2	0	2
85	2	1	2	2	2	9	2	0	2
80	2	2	2	2	2	10	2	99	2
39	2	2	2	2	2	10	1	1	2
97	2	1	2	2	1	8	2	0	2
94	2	2	2	2	2	10	1	0	1
89	99	0	1	0	0	1	1	0	1
5	2	2	2	2	2	10	1	0	1
4	2	2	2	2	2	10	1	0	1
83	2	2	2	2	1	9	2	0	2
90	2	2	2	2	2	10	2	0	2
139	2	2	2	2	2	10	2	0	2
132	2	1	2	2	2	9	2	0	2
84	2	1	2	2	2	9	2	0	2
7	2	1	2	2	1	8	2	0	2
19	2	2	2	2	2	10	2	1	3
148	2	1	2	2	2	9	1	0	1

Scores 99 = No response

Score 999 = Not applicable

Appendix F.5: Total Interactive and Critical Health Literacy Scores

Participant	Interactive and Critical Health Literacy Score
33	40
86	39
96	38
82	41
23	40
26	41
21	33
91	40
151	33
115	33
110	39
20	34
101	39
158	29
92	33
105	20
53	32
98	37
31	40
143	36
28	37
16	37
51	35
46	38
85	39
80	39
39	40
97	34
94	32
89	24
5	32
4	33
83	39
90	36
139	39
132	40
84	37
7	39
19	36
148	34

Appendix G: Full Text Descriptions for Figures and Tables

Text Description for Figure 1

Brief Text Description: ROC Curve for Predicted Probability of Level of Attendance

Summary: This figure depicts the specificity and sensitivity of the 28-item questionnaire. The area under the curve demonstrates that the questionnaire was both specific and sensitive at predicting participants' likelihood of being a regular attender.

Detailed Description: This ROC curve depicts the specificity and sensitivity of the 28-item questionnaire. The y-axis is labeled 'Sensitivity' and ranges from 0.0 to 1.0 in increments of 0.20. The x-axis is labeled 'Specificity' ranging from 0.0 to 1.0 in increments of 0.20. A green line starting at coordinates (0.0, 0.0) with a slope of 1.0 goes diagonally across the graph to the right, displaying the slope of a test that is both sensitive and specific. The ROC curve for the 28-item questionnaire is depicted in a blue line and creates a small rectangle at the top left corner of the graph. The rectangle is outlined at coordinates (0.0, 0.75) and moves horizontally to the right at coordinates (0.2, 0.75) and finally moving up vertically in a straight line, ending at coordinates (0.2, 1.0). Underneath the graph, a table depicts the area under the curve to be 0.956, indicating the 28-item questionnaire is highly specific and sensitive.

Text Description for Figure 2

Brief Text Description: Correlation between Percent Attendance and Age

Summary: This scatter plot diagram depicts the relationship between percent attendance and participant's age.

Detailed Description: This figure is a scatter plot diagram representing the positive correlation between percent attendance and participant's age. The y-axis is labeled 'Attendance (%)' with values ranging from 20 to 100 in increments of 10 percent. The x-axis is labeled 'Age (years)' with values ranging from 15 to 45 in increments of five years. There is a legend in the lower right hand corner of the graph labeling 'Regular Attender' with a blue diamond and 'Low Attender' with a red square. There is a trend line for the regular attender group and a separate trend line for the low attender group. The scatter plot shows a moderate positive correlation in the low attender group. Specifically, the participants in the low attender group have a moderate correlation indicating that the older participants are associated with a higher percent attendance.

Text Description for Figure 3

Brief Description: Correlation between Percent Attendance and Health Literacy Scores

Summary: This scatter plot diagram depicts the relationship between percent attendance and participants' interactive and critical total health literacy score.

Detailed Description: This figure is a scatter plot diagram representing the positive correlation between percent attendance and participant's interactive and critical total health literacy score. The y-axis is labeled 'Attendance (%)' and values range from 20 to 100, in increments of 10 percent. The x-axis is labeled 'Interactive and Critical Total Health Literacy Score' and ranges from 15 to 45 in increments of five. There is a legend in the lower right hand corner of the graph labeling 'Regular Attender' with a blue diamond and 'Low Attender' with a red square. There is a trend line for the regular attender group and a separate trend line for the low attender group. The scatter plot shows a strong positive correlation in the low attender group. Specifically, the participants in the low attender group have a strong correlation indicating that higher percent attendance is associated with a higher interactive and critical health literacy score.

Text Description for Table 1

Brief Text Description: Six Cognitive Sub Scores

Summary: This table details the breakdown for items on the questionnaire. Each of the items on the questionnaire is listed underneath the cognitive process it addressed.

Detailed Description: This table depicts the cognitive process the item on the questionnaire covers. The table has six columns labeling the cognitive processes. Across the top of the table, each cognitive process is listed, starting on the left with 'Apply', followed by 'Understand', 'Remember', 'Analyze',

‘Evaluate’, and ‘Create’. Below each cognitive process heading, the item numbers covered by the cognitive process is listed. There are a total of 4 apply questions, 5 understand, 6 remember, 1 analyze, 5 evaluate, and 2 create.

Text Description for Table 2

Brief Description: Participant Demographics

Summary: This table describes demographic information for the sample.

Detailed Description: The table has nine rows and two columns. The first row is the header with ‘Characteristic’ on the left and ‘Numeric or narrative description’ on the right. Under the ‘Characteristic’ column the first row is ‘Level of Attendance’, which refers to whether the participant was in the ‘low attender’ or ‘regular attender’ group. In the second column, mean percent attendance is listed for the low attender and regular attender group, respectively. The next row below level of attendance is ‘Primary language’ and refers to participants’ preferred language spoken in the home. The participants were either English or Spanish speaking. Row five and six list the number of participants that were English speaking and Spanish speaking, respectively. The next row is participant’s age. Average age as well as the age range for participants is listed under the numeric or narrative information in column two. The final row is participant’s ‘Level of Education’. Under the ‘Numeric or narrative description’ column, the average grade level completed for participants is given.

Text Description for Table 3

Brief Description: Binary Logistic Regression Predicting Likelihood of Regular Attender

Summary: This table displays the statistical findings from the binary logistic regression run to assess which independent variables predicted the likelihood of participant's being in the regular attender group.

Detailed Description: This table consists of nine columns and five rows. The first row is the header row and indicates the statistical value resulting from the SPSS output. The first column is labeled 'Independent variables' and lists the predictive variables tested in the binary logistic regression. The second column is labeled '*B'* and gives the *B* value that you would use in an equation to calculate the probability of a case falling into a specific category. The third column is labeled 'S.E.' and lists the standard error for each variable. The fourth row is labeled 'Wald' and this value tells the contribution or importance of each variable. Next is the fifth column labeled 'df' which represents the degrees of freedom. The sixth column is labeled 'ρ' and lists the significance level for each variable. The values under this column less than .05 indicate that they are significant contributors to the predictive ability of the model. The next column is divided labeled '95% C.I. for Odds Ratio' which is made up of a 'Lower' and 'Upper' bound value. These columns represent that lower and upper value for a 95 percent confidence interval.

Text Description for Table 4

Brief Description: Correlation between Percent Attendance and Health Literacy Scores

Summary: This table depicts the statistical results from the Pearson's correlation test between percent attendance and health literacy scores.

Detailed Description: This table consists of three columns and three rows, making a correlation matrix of nine boxes. The top left hand corner of the first row is blank. The middle column of the first row is labeled, 'Interactive and Critical Health Literacy Score' followed by 'Percent Attendance' in the third column. The second row, first column on the left, is labeled 'Interactive and Critical Health Literacy Score' followed by 'Pearson correlation', 'Significance' and 'N' value. Below this box in the first column is 'Percent Attendance' followed by 'Pearson correlation', 'Significance' and 'N' value. Values are provided in the last two columns of rows two and three.